



How Drug and Alcohol Treatment Programs Can Comply With the 2010 Census

Many drug and alcohol residential programs and half-way houses have been asking how they can cooperate with census takers, as they make their rounds in 2010, without violating the federal confidentiality law and regulations. Programs are concerned about the two ways in which patient-identifying information could conceivably be disclosed: (1) a census enumerator allowed into a program to assist patients in filling out the census forms would learn the identities of patients; (2) the program itself, if it turned over census forms with its residents' names to the Census Bureau, would identify the patients as persons receiving substance abuse treatment.

The Legal Action Center called the Census Bureau to determine exactly what information census takers will be seeking and how they plan to approach residential treatment programs. We believe we have found a way for programs to cooperate fully with census takers without jeopardizing the confidentiality of their patients' identities. In sum, and discussed in more detail below, program staff may obtain training to self-enumerate, thereby avoiding the problem of a census representative interviewing patients directly. In addition, census forms do not require patient-identifying information.

Appointing a program enumerator

According to the Census Bureau program can avoid having a census enumerator visit its facilities if a program staff member volunteers to be trained as a census enumerator instead. That staff member can then conduct the census on the program's premises, distributing census forms to residents, collecting the completed forms (after residents seal them inside individual envelopes), answering any questions, and interviewing residents who cannot complete their forms on their own. This eliminates the first risk to patients' confidentiality -- that an enumerator would learn the identities of patients by visiting the program. We recommend that each program take advantage of the Bureau's offer and designate a member of its staff to serve as a special census enumerator. The Census Bureau provides free training for enumerators through its local district offices. The entire process of being trained and sworn in to conduct the census should take no more than four hours. (You can locate the nearest local district office by calling directory assistance or contacting one of the Bureau's Regional Centers, located across the country.)

Even if a program chooses to conduct what the Bureau calls "self-enumeration," however, the second risk to patients' confidentiality still remains: isn't the program violating the federal regulations if patients' identities are revealed on the census forms?

Fortunately, the census forms do not require any patient-identifying information. According to the Census Bureau, the forms can be filled out using room numbers, patient numbers, or random numbers from one to whatever, if patients do not want to list their names. The Bureau only asks that the program account for each resident somehow. The staff member who is trained as an enumerator should advise patients that revealing their names is optional.

The census forms do ask that people who think they may be counted somewhere else (e.g., as family members or roommates at their permanent home addresses) supply their names and permanent addresses, so that the Bureau can avoid counting people twice. If patients would like to furnish this information voluntarily, they may. (They should know that census data is available only in the form of tabulated statistics, rather than information about individuals, and that the Census Bureau is required to keep all identifying information confidential.) But they are not required to provide their names.

If patients have not given their names, the program's enumerator can turn the forms over to the Census Bureau without compromising any patient's confidentiality: the program is not making any disclosure under the federal regulations because there is nothing in the forms to identify any patients. If a patient does write his or her name or home address on the census form, the program should get the patient to sign a consent form permitting it to turn the census form over to the Census Bureau. This is

because, although the patient himself is voluntarily disclosing his identity, theoretically the program is making a patient-identifying disclosure when it turns the census form over to the Bureau.

Relying on the Census Bureau enumerator

If a program cannot get a staff member trained and sworn in as an enumerator, one of the enumerators will have to visit the program. Because these enumerators will be visiting a variety of types of facilities, they may not be familiar with the special restrictions on disclosing patient identities that drug and alcohol facilities face. For this reason, we recommend that the program director contact the local district office as soon as possible to discuss the best way for the program to help in the census effort.

Unfortunately, the Census Bureau cannot permit enumerators to leave census forms with program staff who have not been trained and sworn in as enumerators. This means an enumerator has to deliver the census forms by hand to each patient or, if any patients cannot complete the forms on their own, interview those patients in person. Obviously, the program cannot permit this without getting the written consent of every patient in advance or designating a room where the patient can voluntarily go to see the enumerator.

Programs should warn their enumerators that gathering consent forms will take time and should tell patients that they do not need to disclose their names or any other information which might disclose their identity to the enumerator. Programs should also warn the enumerators that, because of the federal confidentiality regulations' restrictions on redisclosure, they may not disclose to anyone else, directly or indirectly, that a person they have seen in the program is a drug or alcohol patient. (Of course, any information the patient provides on the census form itself would qualify as a self-disclosure to the Bureau of the Census and may be redisclosed within the Bureau as that agency's regulations provide.) The enumerators will already be very sensitive to the need for confidentiality, because federal law prohibits enumerators from disclosing any information they receive while performing their duties; confidentiality is one of the focal points of their training and the major subject of their sworn oath.

If some patients do not want to meet with the census enumerator, the program must honor their wishes and shelter them from the census enumerator. The enumerator will ask the program or facility director to supply the basic information needed to complete the census forms for such patients. The program should feel free to provide as much information as can be disclosed without identifying the patients involved. (In fact, Bureau as fully as they can.)

We hope that every program will be able to have an enumerator trained from its own staff. That would be the best way to ensure that everyone is counted in the 2010 census and that the confidentiality of patients' identities remains secure. However, any program that cannot manage to "self-enumerate" should know that it should be able to work out a suitable alternative with the Bureau's enumerators.